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ABSTRACT

Strategies and techniques for developing community-based programs for mentally retarded persons in rural areas must take into consideration local circumstances, resources, and characteristics. Rural norms such as overt racial segregation, social conformity, the importance of church, and the stigma of obtaining human services for personal problems must be understood and accepted. Professional programs must win approval of, and work in accordance with, informal or "natural services systems" which often provide services for which there are no formal organizations. Complicated community dynamics make the selection of local staff for rural service organizations a complex problem. Regionalized programs are more easily coordinated and more economically feasible in rural areas (where a "unit" of service costs four times more than in urban areas), but rural parochialism makes acceptance, creation, and maintenance of such programs difficult. "Purchase of Service" contracts are an attractive alternative for providing human services in rural areas if some service organizations exist. Service professionals in rural areas face special problems of professional isolation, broadly generalized skills and knowledge, and community acceptance based on other than professional considerations. Programs and services designed for urban areas must not be exported to rural areas. (SB)

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The Delivery of Services to Mentally Retarded Persons Living in Rural Areas: Context, Problems and Issues

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INTRODUCTION

Efforts to develop community-based programs in rural areas must grapple with problems and issues somewhat different from those encountered in urban areas. Unfortunately, the special needs and problems of rural areas do not get much attention. Referring to this problem in the United States, Popp (1975) states that the

> . . . special needs of rural areas seem to have been neglected in the nation's efforts to recognize and cope with the problems of mentally retarded persons. When the federal government arranged in 1964 for "comprehensive" state-wide mental retardation studies throughout the country, only a very few states ever mentioned the specific needs existing in rural areas. Yet rural areas still comprise a large part of the nation. . . [p. 129].

Cochran (1976) has offered convincing arguments concerning the existence of a pro-urban and possibly an anti-rural bias within various federal agencies, including the United States Department of Health, Education and Welfare and the Department of Agriculture. This bias results from the fact that most of those in decision-making positions are from urban areas, now live in urban areas, have work experience in urban programs, received their professional education in urban universities and hear and read most about urban problems and programs. They are simply uninformed about rural areas. They are more familiar with what is going on in urban areas and how things work in urban areas. Or, if one wishes to view it from a behavioral point of view, one could conclude they have not been rewarded for paying attention to people from rural areas. Or, conversely, they have been rewarded for paying attention to urban areas.

A 1966 Wisconsin project identified a number of special problems relating to the development of community-based programs for mentally retarded persons in rural areas. The following is from Popp (1975):

A. In a rural area the understanding and awareness of the retarded's needs and the subsequent impetus to serve him has suffered from the relative lack of exposure to publicity, information, and educational effort.
B. Services for the retarded have not developed in rural areas due to the mechanical problems involved in bringing people together in an area of low population density.
C. In a rural area there is often a lack of facilities such as day care, sheltered workshops, and special classes to serve the retarded.
D. Most rural areas lack diagnostic and treatment centers.
E. Rural areas lack an organizational structure for proper identification, treatment, and referral of the retarded and their families.
F. There is an extreme lack of trained professionals, such as psychologists, social workers, public health nurses and physicians, who can offer service to the retarded or their families.
G. The rural retarded and their families have long been unaware of any alternatives to strict custodial care in the home.
H. People in rural areas often have low expectations for their normal child, as well as the retarded, and are unable to see the value of training and education.
I. There is often a stigma attached to family counseling in a rural area, and the fixed point of referral may be located in a clinic or welfare department. Where little stigma is attached, such as the public health nursing service, this office is understaffed in a rural area.
J. Neighbors in a rural area often have less experience with and understanding of the retarded child than their urban counterparts.
K. Parents of the retarded in a rural area are often poor and cannot afford the cost involved in transportation or the child care necessary to attend parent group meetings or take advantage of counseling and diagnostic services for their retarded child [pp. 129-130].

Twelve years later, these problems still exist in most rural areas of the United States. If services and opportunities are to be expanded for persons who are mentally retarded and living in rural areas, planning and program development must be built upon rural resources and characteristics. Moreover, we need to reexamine our tendency to try to "export" urban planning concepts and urban programs into rural areas. Rather, our strategies and tactics must be individualized to local circumstances and the rural condition.

Several factors must be considered in the development of a comprehensive service system for the mentally retarded. These are: (1) land area, (2) population, (3) economics, (4) professional resources, (5) organizational resources, (6) consumer or client characteristics and (7) transportation. The remainder of this paper will focus on several of these factors and elaborate on some of the problems and issues of program development and service delivery in rural areas.

WHAT IS A RURAL AREA?

According to Millar (1977):

> Canada is a country of approximately twenty-three million people, occupying a landmass of over 3.8 million square miles. This area is over forty times the size of Britain and eighteen times the size of France.

He goes on to note that:

> 1 - Almost 25 percent of the population of Canada resides in the three metropolitan centres of Toronto, Montreal, and Vancouver.
> 2 - Two out of every three Canadians live in two of our ten provinces: Ontario and Quebec.
> 3 - Ninety percent of the people of Canada live in a thin east-west line within 100 miles of the U.S.-Canada border. . . .
>
> Despite its size, Canada is a highly urbanized country with vast areas uninhabited or sparsely populated. The Northwest Territories for example makes up one-third of the country's area (over one million square miles), yet the population of this portion of the country is under forty thousand people [p. 148].

Essentially, a rural area is one which is characterized by a sparseness of population or a low density. In other words, it is a relatively large land area occupied by a relatively small number of people.

Millar (1977) says:

> Attempting to define exactly what constitutes a "rural" area in Canada is a difficult task. Most "rural" areas in Canada are unique unto themselves and bear little resemblance to other areas which we would also label "rural." Some characteristics however are not exclusive to any one region. Included among these are a

> low density of population, relative isolation from major centres, harsh climatic conditions marked by long winters and short summers, an economic base rooted in primary industries such as mining, fishing, logging, and farming, and a high proportion of native Indians relative to the white population. . . .
>
> The industrial and governmental bureaucracies which make decisions affecting almost every aspect of the rural inhabitant's life are centered far away from the scene their actions affect. For the rural person then, decisions are seen as being made "down south," or "down east," with the accompanying feeling of powerlessness and separation from this activity. This problem is compounded in Canada by the fact that large amounts of our primary industry are under foreign ownership and control, a fact which only serves to enhance the sense of powerlessness and the lack of control over one's destiny.
>
> This separation and remoteness has created in many rural areas a distrust in central authority, particularly as represented by government [p. 149].

If Millar's perceptions are accurate, this sense of distrust of a central government has serious implications for the design and delivery of services in rural areas.

THE RURAL CONDITION

Increasingly, rural communities resemble urban or suburban communities (Warren 1972). While traditional urban-rural differences are becoming blurred, remnants of a rural culture still exist. Rogers and Burdge (1972), for example, note that rural people (mainly farmers and ranchers) exhibit certain attitudes and values which are different from those of people in urban areas. In areas where rural culture still persists, it must be considered in planning and service delivery.

Rural culture and characteristics have obvious relevance to the design and management of services in accord with the normalization principle. Bronston (1976) states:

> The essence of that principle requires the use of culturally normative means and methods . . . to offer a person life conditions at least as good as the average citizen . . . and as much as possible enhance or support his/her behavior experiences, status and reputation. By culturally normative means, we speak about using those techniques, tools, media, and methods that are most familiar and valued in our culture [p. 495].

Since the application of the normalization principle is "culture specific," it is interesting to ponder questions such as: (1) What are the "normal" conditions of the average rural citizen? and (2) To what extent should programs in rural areas incorporate the life experiences, values and expectations of rural people?

Ginsberg (1976) has identified a number of conditions which are "normal" for the typical rural American. I expect most of these are also descriptive of rural life in Canada. Some are the following:

> Rural dwellers often lack access to high quality education, highways, museums, libraries and entertainment. . . . In a small town the choice [of entertainment] may be between a few bars and one movie.
>
> There is simply not much to do with one's free time. . . . The rural wealthy may take world cruises or fly to a city for the weekend but the rural dweller of moderate means lacks such choices.
>
> If one is seriously ill the nearest urban hospital may be used, with all the attendant problems of transportation, isolation from family and friends and the added expense.
>
> Some small towns have no physicians or dentists. Others must rely on circuit riding healers, who serve each of several small towns one or two days a week. . . . Still others must make do with less adequately prepared professionals than they could find in cities.
>
> Rural communities tend to be one or two industry or company towns [e.g., farming, agribusiness, mining]. Frequently, the industries are unattractive to young men and women.
>
> Many rural areas--perhaps most--lack efficient, low cost public transportation. But the available jobs may be miles away. Thus, ownership of an automobile is often a necessity for a worker in a rural area.
>
> One has little difficulty in finding overt racial segregation, lack of suffrage, corruption. . . . Rural governments are often run by the local power structure much in keeping with the descriptions . . . found in the writings of Floyd Hunter (1969). The Lions Club, Rotary Club, Methodist Church and city council are frequently governed by the local wealthy citizens, no matter who the officially designated presidents, mayors or councilmen are.
>
> American Indians, Chicanos and Blacks continue to report being singled out for special punishment by local law enforcement officials who are products of the same power elite that control everything else. . . . No case is being made to support the idea that rural officials are less concerned about human rights than their counterparts in cities. However, cities have a number of other institutions such as civil rights organizations, legal aid agencies and government offices that conduct monitoring activities that,

> in turn, make officials more responsive to the protection of human rights and less inclined to act inappropriately. Rural communities are too small to support such institutions.
>
> . . . The church plays a major role in rural communities, perhaps a greater one than in urban areas. One's religious affiliation is an important consideration for newcomers to small towns.
>
> Impersonal services are uncommon in a setting where everyone knows everyone else or at least everyone else's relatives.
>
> . . ..Taking social or political positions that differ from those dictated by the conventional wisdom of the rural community may lead to social and professional ostracism. . . .
>
> Those who are too quick to tell others their faults are unpopular in both the metropolis and the village. But the results of such behavior are more rapid, persuasive and dramatic in the [rural community] [pp. 3-7].

What does all this mean? It means that there are both positives and negatives associated with most rural characteristics and norms. It does not mean that those of us interested in expanding services for the mentally retarded should unquestionably support all rural norms. However, we must be able to understand and accept those norms and work for change at a pace acceptable to the rural people themselves.

THE FORMAL AND INFORMAL SERVICES OF RURAL AREAS

Recent contributions to social service literature (see, for example, Buxton, 1973; Segal, 1973; Koch, 1973; Mermelstein and Sundet, 1973; Millar, 1977) have identified features of service delivery that are unique to rural areas. The literature also indicates that strategies and programs developed in urban areas cannot be simply "transplanted" into rural areas or small towns.

While it is true that rural communities have fewer formally organized professional services and agencies, it is a serious error to assume that a particular service is not being provided simply because a formal organization does not exist to provide that service (Ginsberg 1973).

It is important to remember that informal systems of service are common to rural areas. Patterson and Twente (1971) term these informal arrangements "natural service systems" or "natural helpers." More recently, the National Association of Social Workers has published a book in which it refers to these informal services as "natural helping networks" (Collins and Pancoast 1976). These natural service systems include neighbor helping neighbor, loans among friends, service club involvement in helping specific families or specific handicapped individuals, hiring of people who need a job rather than people who have the skills, etc. These informal arrangements tend to develop in the absence of formal services. The rural professional must win access to the natural service system and insure that his or her formal and agency-based approach works with the informal or natural arrangements. This means developing and nurturing friendly relationships with local ministers, business people, physicians, teachers, service clubs, agricultural extension agents, community leaders, etc. It has been observed that service clubs play an especially important role in the informal service system of rural areas (Ginsberg 1969). These informal networks lack the sophistication and knowledge base of professionally organized programs but they do perform a valuable function and are usually supported by the influential citizens and community leaders making up the power structure. If a new formal plan for the development of human services poses a threat to these informal service structures, it may encounter considerable resistance. However, Wylie (1973) has observed that this informal helping network may be more of an asset than a liability in developing a new formal service system in rural areas.

> Here is a mighty resource for the social planner--a pool of people accustomed to helping each other, a pool of people already accepted and identified by the community as helping agents, and people who can be easily identified . . . the challenge is to strengthen and expand this natural network by preserving the naturalness rather than imposing professional standards and norms. In other words, . . . what we have there already may be quite good in its own right [p. 26].

Despite some obstacles to change in rural areas, unique potentials are also present. One is the sense of pride and community spirit that exists in many rural areas. These elements are especially strong in relation to self-help activities and "taking care of our own." If new program ideas and plans are generated from within the community and are supported by respected citizens, the rural community is capable of rapid and surprisingly innovative action. On the other hand, plans or programs that are imposed upon small communities by outsiders often meet with passive resistance or fail to win support necessary for implementation. Thus, it is essential that parents, natural helpers and members of the local power structure be involved in any planning process that affects rural communities. Not only is their involvement necessary to win acceptance of new concepts and new programs, but many of these same individuals are needed to form the nucleus of volunteers who are so necessary to rural programs. As one might expect, it is no small task for regional or government planners to strike a balance between a community's unique desires and values and the bureaucratic requirements of large scale social planning and funding constraints.

In certain areas of the United States a back to nature phenomena has been observed. Many young and well educated urban residents are moving to rural areas, especially those areas that are scenic and characterized by a mild climate. This has meant that very talented individuals (e.g., special education teachers, speech and language clinicians) now reside in some

small rural communities. They can and should be mobilized to provide valuable services to persons who are mentally retarded.

It should be noted, however, that those wishing to escape the urban scene should not move to a rural community expecting an uncomplicated life. The dynamics of rural communities are far from simple. According to Ginsberg (1969):

> Rural communities are often as sociologically complex as urban communities. Many of their characteristics may be based upon little remembered but nevertheless influential historical events focused on family conflicts, church schisms, and a variety of other occurrences which may deserve the status of legends [p. 30].

Unless someone in the community chooses to inform you of these "historical events," you may live in a community for many years and remain baffled at the local behavior and the patterns of cooperation and noncooperation.

The history of interpersonal relations in the small community has an obvious effect on service delivery. Who runs or staffs a program may have much to do with whether or not a particular service is utilized by particular families. Thus, in the selection of staff, their personal background or image in the community is of critical importance, sometimes of more importance than their professional competence.

The provision of services within the Indian communities common to many rural areas presents an even greater challenge. Cultural difference and intertribal conflicts can completely baffle the White, middle class professional or social planner. The usual approaches to service delivery and notions of professional/client relations are contrary to the tradition of noninterference. Good Tracks (1973) explains noninterference as follows:

> In native American society, no interference or meddling of any kind is allowed or tolerated, even when it is to keep the other person from doing something foolish or dangerous. When an Anglo

> is moved to be his brother's keeper and that brother is an Indian, therefore, almost everything he says or does seems rude, illmannered or hostile.
>
> . . . The Indian child is taught that complete noninterference with all people is the norm, and that he should react with amazement, irritation, mistrust and anxiety to even the slightest indication of manipulation or coercion [pp. 30-31].

The value we place on early intervention, crisis intervention, behavior modification, parent training, advocacy, etc. indicates that most of us have been taught that interference is acceptable, even desirable.

THE RURAL FAMILY

It is difficult, perhaps impossible, to formulate valid generalizations about the rural family. Clearly, rural families are experiencing the same stresses and strains that affect all modern families. Yet there are hints that there are a few differences between urban and rural families. Rogers and Burdge (1972) state:

> The family is changing, but rural families have tended to lag behind urban families on many of the trends and changes taking place. For example, rural families are still larger in size than urban families; they have retained more of the traditional family functions, are more father-centered and have fewer divorces [pp. 194-195].

Our approaches to service delivery should recognize such differences and build upon them. Berkley (1976), for example, has observed how the tradition of hospitality can be utilized in gathering research and diagnostic data from rural families. For example, she states that:

> Refusing hospitality is a gross mistake in a rural setting. I was always served tea or coffee and frequently was invited to stay for meals. Mealtime is usually the only time the entire family is assembled at once. The atmosphere around the table is much more relaxed and decidedly more information can be obtained . . . than in a formal interview setting [p. 3].

Berkley also states that many rural families felt their mentally retarded child was fairly well accepted by community people.

> . . . This observation seemed to come more from persons who had lived in the community . . . for a relatively long period . . . and had established good community relationships. . . . There also seems to prevail an air of the "extended family" in rural settings--emotional and psychological support of a family who has a handicapped member comes from friends and neighbors--as contrasted to our "professional extended family" that exists in large urban settings in the form of specialized services and . . . professionals [p. 6].

Because formal human service organizations are few and far between, many rural families have had little or no experience with such organizations. Many do not know how to find or utilize the few services that do exist. Thus, quality information and referral service and the professional roles of social broker and advocate-ombudsman take on added importance in rural areas.

CONFIDENTIALITY IN SERVICE DELIVERY

Because of the relatively small number of people living in rural communities, the residents know just about everyone around. Ginsberg (1973):

> Scrutiny of everyone by everyone else if often characteristic of rural communities and what one does in his or her spare time, in the evenings and on weekends, is often a matter of public concern and discussion [p. 9].

That lack of privacy and anonymity presents some obvious problems for both the client and the professional.

The client or potential client may worry that everyone will know that he/she is seeking professional help. So long as the services sought are for rather tangible problems (e.g., physical therapy, medical treatment), there seem to be few conflicts. If, however, the individual needs professional help with personal or family problems, social or emotional ones, he/she may avoid being seen at agencies or offices providing such assistance. While working in a rural area of Colorado, this author observed that some individuals and families preferred to drive fifty or

sixty miles to a strange town in order to keep appointments with traveling mental health teams even though the team was in their own community on a regular basis.

The rural professional is often placed in the rather awkward position of serving on committees or attending social and community gatherings with his/her clients. This can make both client and worker a bit uncomfortable, especially if they have shared highly personal matters.

PROFESSIONAL RESOURCES

Rural communities can rarely support or afford a variety of professionals with specialized knowledge or skills. Thus, as is true for most human service professionals in rural areas, the professional working in rural programs for the developmentally disabled is forced by circumstances to become somewhat of a generalist. Few are able to specialize. Most rural professionals work with clients having a wide variety of problems and needs and most must carry administrative, planning and community organization responsibilities in addition to direct service duties.

The author has observed a fairly high rate of burnout among professionals in rural areas, especially those who must do extensive traveling. Burnout is probably also related to the breadth of their duties and feelings that they have to know a little about everything but are denied the satisfaction of feeling they are really competent in one special area.

Because specialists are not available and because rural professionals have fewer opportunities to function as members of teams they need to have a broader knowledge base and a greater range of skills than their urban counterparts. Very important skills are those related to the training and

utilizing of the volunteers and paraprofessionals who must often carry heavy responsibilities in rural programs. Programs in continuing education and staff development are vital to agencies which are staffed by many nonprofessionals and by professionals who must carry a wide range of responsibilities.

It is also important to note that the professional in rural areas must often assume roles quite unlike those he might have in a large metropolitan area. In comparison to urban areas, rural area residents place less value on professional credentials and expert opinion. Whether or not a professional's suggestions are accepted often depends on his informal behavior and how he relates to ordinary people in social situations.

Because many professionals live and work in small, isolated communities, they often suffer from loneliness and a lack of professional stimulation. Supervision and consultation are often unavailable. Professional organizations are generally weak because of the small number of professionals in any one community and the great distance between communities. Agency libraries, if they exist at all, are usually inadequate.

Because so few agencies offer employment opportunities, rural workers are understandably reluctant to engage in actions which might jeopardize their jobs (e.g., advocacy, public criticism of the system). A protest resignation or an involuntary loss of one's job because of boat rocking often means that the worker must abandon employment in the human service field or leave the state to secure similar employment.

Unusual dress and unorthodox behavior can have an immediate and devastating effect upon a professional's ability to function in the community. Community acceptance is precious and essential to the rural

practitioner, and it must be nurtured constantly. Community acceptance comes slowly and is based almost entirely on personal and informal behavior rather than professional credentials, previous experience or formal education. A newcomer to an area is always treated as an outsider. It may take years before he or she feels a part of the community. Some have said that one does not really belong to a rural community until he/she has a blood relative buried in the local cemetery.

ECONOMIC ISSUES IN RURAL AREAS

It is commonly assumed that a unit of social or human service costs about four times more in a rural area than in an urban area. This unit cost includes both the direct or indirect costs to the client (e.g., fees, time away from work, travel expense) and the agency. The expense of travel by staff and/or clients are key factors which increase the cost of service.

A lack of coordination among community programs is a common problem within all human service networks, including the mental retardation service system. A major cause of this problem is the multiple sources of private and governmental funding utilized in the provision of services. Each source has guidelines which regulate the use of funds, the type of service that can be provided and eligibility. Thus, coordinated funding appears to be a prerequisite for a coordinated service delivery system.

The small number of mentally retarded persons in any one community makes it economically unfeasible for all communities to develop a comprehensive service system. Rather, services must be regionalized. Ideally, they should be planned and administered at the regional level (Scheerenberger 1974).

For the rural area in the United States, regionalization means the utilization of some type of multicity or multidistrict organization. Given the fact that most rural communities or areas are rather provincial in their outlook, the creation and maintenance of such an organization can be a frustrating administrative experience, but a good education in rural politics.

ORGANIZATIONAL RESOURCES IN RURAL AREAS

Purchase of service contracts are commonly used to provide public funding to private organizations. Gilbert and Specht (1974) note that the purchase of service funding mechanism has both advantages and disadvantages.

> The major virtue of these forms of subvention to private and voluntary organizations is that they provide a varied means for starting government programs quickly. They avoid the rigidities of civil service and bureaucracy. Such characteristics are advantageous for public programs for small special groups of clients and for experiments or demonstrations.
>
> For the voluntary agency, the obvious advantage of these arrangements is access to the public coffers as additional sources of income. But they pay a price. To the extent that voluntary agencies are supported by government funds, they forfeit some degree of autonomy. Consequently, these agencies are limited in their ability to function as agents for the expression of new or unpopular ideas, as critics of public services, and as the guardians of pluralistic values. In the extreme, voluntary agencies may simply become an instrument of government policy [p. 150].

In rural areas the flexibility of this mechanism is especially attractive because it permits the shaping and molding of programs to fit local situations, traditions and values. As previously indicated, programs designed and operated by local people are more likely to be accepted and supported by the community even though they are state funded. The community tends to view them as "our programs." By comparison, government-operated programs have a harder time winning community support.

The purchase of service mechanism, however, does face some special problems in rural areas. The approach presumes that private human service organizations exist and that they are capable of modifying or expanding their program so as to provide purchaseable services. Well established private agencies are rare in rural areas. Those that exist tend to be small and fragile. Many are operated and staffed by volunteers or have a paid staff of one or two people. Because they frequently lack adequate professional resources, these organizations are seldom capable of planning and developing the sophisticated training and behavioral shaping programs needed by the more severely retarded or those with behavioral problems.

Not infrequently, agency board members and key decision makers within these small organizations are unaware of successful programs in other parts of the country. Innovations or program changes are more likely to be based on the experience of a program in a nearby community than on ideas derived from national conferences such as this one or from professional literature.

In some cases, a new nonprofit corporation is created for the specific purpose of securing public funds for the provision of badly needed services. Unfortunately, a newly created organization must devote much of its time and energy to maintenance functions. Only after it gets on its feet is it capable of devoting full attention to providing service. Thus, a new private service organization in a rural community may have a difficult time adhering to performance standards established by the state funding agency. This places government agencies in an awkward position of funding programs that leave much to be desired in the way of quality services.

Associations for the mentally retarded and other self-help-advocacy or consumer groups in rural areas are usually small and relatively weak.

Physical distance between families and the reality that there is a finite limitation on human energy and commitment makes it difficult to muster and maintain a stable advocate organization.

CONCLUSION

Rural areas are different from urban areas. Programs and services developed in metropolitan areas and designed to serve persons living in urban areas cannot simply be replicated or transplanted in rural areas or the small community. Rural-urban differences must be recognized. Planning and service delivery in rural areas must be built upon the rural culture and characteristics. This paper has attempted to identify some of those characteristics and offer possible implications.

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